How Do Children Talk About Sleepiness and Fatigue?

Claudia June Human

This thesis is submitted in partial fulfilment of the Honours degree of Bachelor of

Psychological Science (Honours)

\The School of Psychology
University of Adelaide
Faculty of Health and Medical Sciences
September 2020

Word Count: 9450

Table of Contents

Abstract 6
Declaration
Contribution Statement
Acknowledgements 9
Chapter 1: Introduction
1.1 Sleepiness
1.1.1 Conditions and Circumstances Associated With Sleepiness
1.1.2 Impacts of Sleepiness on Children's Wellbeing and Development12
1.2 Fatigue
1.2.1 Conditions and Circumstances Associated With Fatigue
1.2.2 Impacts of Fatigue on Children's Wellbeing and Development14
1.3 Distinguishing Between Sleepiness and Fatigue in Children
1.3.1 Issues and Importance of Precise Diagnosis
1.3.2 Limitations of Current Measures of Sleepiness and Fatigue16
1.3.3 Suggestions for Future Measures
1.4 Current Study20
Chapter 2: Methods
2.1 Participants21
2.2 Procedure24
2.3 Materials24
2.4 Analysis

Chapter 3: Results	
3.1 Objective Descriptions	27
3.1.1 Cause	27
3.1.2 Behavioural Response	30
3.2 Subjective Descriptions	35
3.2.1 Body-Based Sensations	35
3.2.2 Mind-Based Experiences	42
Chapter 4: Discussion	49
4.1 Overview	49
4.2 Objective Descriptions	49
4.2.1 Causes Which Distinguish Between Sleepiness and Fatigue	49
4.2.2 Similarities in Behavioural Responses	49
4.3 The Overlap of Objective and Subjective Descriptions	50
4.3.1 Cognitive and Behavioural Responses	50
4.3.2 Social Implications of Emotion-Based Behaviour	52
4.4 Subjective Descriptions	53
4.4.1 Distinguishing Features of Body-Based Sensations	53
4.4.2 Emotional Fatigue	54
4.5 Children's Ability to Distinguish Between Sleepiness and Fatigue	55
4.6 Strengths	55
4.7 Implications	56

4.8 Limitations and Suggestions for Future Research	57
4.9 Conclusion	58
References	59
Appendix A: Visual and Audio Interview Prompts	70

Table 1: Participant Demographic Information

Abstract

Sleepiness and fatigue experienced excessively or chronically are associated with numerous negative impacts on childhood development and wellbeing. The overlapping nature and lack of consensus for definitions of these symptoms within childhood may contribute to misdiagnosis, as does the lack of research – which has focused on adult populations and quantitative methodologies to date. Similarly, current measures of child sleepiness and fatigue are typically derived from adult measures, thereby neglecting the child's perspective and limiting the understanding and measurement of these phenomena in children. The present study is the first qualitative examination of children's own language around the concepts of sleepiness and fatigue. Semi-structured interviews were conducted with primary school children from Adelaide, South Australia (N = 42) with the sample stratified by gender, school grade (three, five, & seven), and socio-economic status. Interviews presented eight visual and audio scenarios, and participants' responses to these were recorded, transcribed, and thematically analysed using a realist epistemology. Analysis led to the identification of two overarching themes: 1) language describing 'objective' experiences which can be observed by others and 2) language describing 'subjective' experiences which cannot be observed by others. Four subthemes exist: 'causes' and 'behavioral responses' (objective descriptions), and 'body-based sensations' and 'mind-based experiences' (subjective descriptions). Importantly, across themes, children shared various features which distinguished between sleepiness and fatigue. Based on these findings, there is potential to develop a developmentally sensitive self-report measurement tool designed to accurately identify and distinguish between sleepiness and fatigue in children.

Keywords: sleepiness, fatigue, children, qualitative, thematic analysis

CHILDREN'S TALK ON SLEEPINESS AND FATIGUE

7

Declaration

This thesis contains no material which has been accepted for the award of any other degree of diploma in any University, and, to the best of my knowledge, this thesis contains no material previously published except where due reference is made. I give permission for the digital version of this thesis to be made available on the web, via the University of Adelaide's digital thesis repository, the Library Search and through web search engines, unless permission has been granted by the School to restrict access for a period of time.

Claudia June Human

September, 2020

Contribution Statement

In writing this thesis, my supervisors and I collaborated to generate a research question for existing, ethically approved interview data of 42 children, which involved scenarios relating to sleepiness and fatigue. I conducted the literature search, reviewed audio recordings of interviews against transcriptions, and performed qualitative analysis using NVivo 12 under the guidance of one of my supervisors. I wrote up all aspects of the thesis.

Acknowledgements

First and foremost, I would like to express my appreciation for both my supervisors, Dr. Mark Kohler and Associate Professor Jaklin Eliott, who have been forthcoming with helpful advice and guidance throughout this project. They have encouraged me to believe in my own ability as an 'expert' on my topic and to create research I am proud of.

I would like to thank my newfound friend and colleague, Sophie, a fellow researcher who gave her time to check over my analysis and therefore help to improve the quality of my research.

My longstanding friends, who have patiently waited for the submission of my thesis to hold me accountable for a great lack of socialisation over the year.

My parents-in-law who have welcomed me into their home and who were always ready with a cup of tea, or sympathetic ear when I needed it. And to Chloe and Sookie who have kept me in quiet and sometimes moody company while studying from home.

My parents, who have always believed in me without doubt and kindly let me walk my path. And to my brother who gently brings me back down to earth.

My loving and very patient partner, Gabe, who always listens, encourages, and makes me laugh.

Finally, I would like to thank each and every child who gave their insightful, unique, and at times quite amusing perspectives to this study.

Chapter 1: Introduction

A sense of tiredness is typically based on feelings of either sleepiness, fatigue, or a combination of these. Although sleepiness and fatigue are distinct symptoms, they possess overlapping causes and outcomes. The general complaint of tiredness becomes problematic in a clinical setting, where ambiguity in definition can lead to misdiagnosis and therefore lack of application of appropriate treatment (Shahid et al., 2010; Shen et al., 2006). In an attempt to clarify sleepiness and fatigue amongst the heterogeneity of definitions that exist, Pigeon et al. (2003) operationalised sleepiness as characterised by drowsiness, sleep propensity, and decreased alertness, and fatigue as characterised by weariness, weakness, and decreased energy. Nonetheless, consensus is yet to be reached on key distinguishing features between these constructs (Shen et al., 2006).

1.1 Sleepiness

Sleepiness, while a normal experience of everyday life, becomes problematic when it occurs excessively and at inappropriate times. Excessive daytime sleepiness (EDS) is defined by the International Classification of Sleep Disorders, Second Edition (ICSD-2) as "the inability to stay awake and alert during the major waking episodes of the day, resulting in unintended lapses into drowsiness and sleep" (Morrison & Riha, 2012, p. 110). The exact prevalence of EDS in children is not known but has been reported as low as 2% to as high as 25% (Ludwig et al., 2019a). The discrepancies in prevalence rates could be due to differences in adult-based definitions and measures used in studies with children. However, unlike adults, children may not necessarily realise they are sleepy and may communicate their feelings through hyperactive or inattentive behaviours, which could present issues for the accurate identification of sleepiness in children (Dahl, 1996; Hoban & Chervin, 2001). The precise diagnosis of sleepiness in children is important due to the plethora of problematic causes and impacts on healthy childhood development.

1.1.1 Conditions and Circumstances Associated With Sleepiness

Between 25% to 50% of children experience sleep difficulties at some point in childhood (Carter et al., 2014; Kazaglis et al., 2016; Owens, 2008). Sleep deprivation and disruption are the main reasons why a child experiences sleepiness outside of the typical daily fluctuation (Nevsimalova, 2017), and various conditions and circumstances can affect the amount and quality of sleep a child gets. These factors can be internal or external in nature, such as medical conditions and sleep disorders compared to behavioural and environmental factors. Conditions like epilepsy and chronic pain can cause difficulty in attaining adequate sleep (Fallone et al., 2002). Obesity, heartburn, asthma, and the use of asthma medication are also strongly correlated with EDS (Calhoun et al., 2011; Jones et al., 2017). Sleep-related disorders characterised by EDS in its most severe form include narcolepsy, idiopathic insomnia, and Klein-Levin syndrome (Moreira & Pradella-Hallinan, 2017). EDS is often a secondary symptom of sleep disordered breathing (SDB), which ranges from primary snoring to obstructive sleep apnea syndrome, periodic leg movement disorder and restless leg syndrome (Nevsimalova, 2017). Nightmares, night terrors, and sleep walking can also significantly disrupt sleep, resulting in EDS (Carter et al., 2014). The home environment and behaviours around bedtime have been associated with the presence or absence of sleep problems. Behavioural sleep disorders involve inconsistency in bedtime routines (limit setting disorder) and the learned necessity for special conditions around falling asleep such as being rocked or watching television (sleep onset associated disorder) (Carter et al., 2014). The increasing use of technology around bedtime is especially relevant as it has adverse associations with sleep outcomes (Hale & Guan, 2015). Finally, living in a home with an ill family member, having a step-parent reside at the home, or living in foster care are all associated with sleep difficulties in children (Paavonen et al., 2000).

1.1.2 Impacts of Sleepiness on Children's Wellbeing and Development

EDS in childhood is associated with numerous negative impacts on emotional, cognitive, and behavioural wellbeing and development. Sleepiness is strongly associated with decreased positive mood, anxiety and depression (Alfano et al., 2009; Calhoun et al., 2011; Nevsimalova, 2017). Sleepy children also exhibit difficulties with irritability, emotional lability, and low thresholds for expressing frustration and distress (Dahl, 1996). As well as causing emotional distress, sleepiness can affect a child's cognitive flexibility, abstract thinking, motor skills, attention/response inhibition, memory, and focused attention (Dahl, 1996; Fallone et al., 2002). Due to an inability to effectively process thought or regulate emotions, sleepy children will usually display sleepiness through behaviour (Pesonen et al., 2010). Sleep-deprived children have been observed to exhibit inattentive behaviours, such as daydreaming or staring in a dazed manner, suggesting that such children should be checked for sleep problems (Fallone et al., 2001). Calhoun et al. (2012) found that EDS is associated with parent reports of learning, attention/hyperactivity, and conduct problems. They suggested that EDS affects a child's ability to pay attention, regulate their level of activity, and therefore affect learning.

Children with attention deficit hyperactivity disorder (ADHD) have an increased risk of sleepiness as a result of potential underlying sleep disorders, such as SDB, effects of prescribed psychostimulant medication, and co-morbid behavioural disorders (Fallone et al., 2002; Golan et al., 2004). Hypoarousal theory suggests that children with ADHD are sleepy and their behaviours are an attempt to stay awake and alert (Weinberg & Harper, 1993). This theory is somewhat supported by the observed benefits of psychostimulant medication (Golan et al., 2004).

As a result of these interrelated emotional, cognitive and behavioural deficits, sleepiness can markedly affect children's performance at school. Sleepiness is associated with

worse school performance, self-perceptions of struggling at school, negative attitudes towards teachers and school, and other negative school-related outcomes (Bruni et al., 2006; Dewald et al., 2010; Ludwig et al., 2019a; Perfect et al., 2014).

1.2 Fatigue

Fatigue, like sleepiness, is experienced universally in the short-term with identifiable causes. However, when it becomes excessive and chronic, it poses a threat to wellbeing and quality of life (Jason et al., 2010). Chronic fatigue syndrome (CFS) is characterised by severe, disabling fatigue experienced for at least three months and can also be accompanied by headaches, cognitive problems, dizziness, and post exertional malaise (Crawley, 2017). Fatigue, more generally, can be further distinguished into physical and mental fatigue. While physical fatigue refers to the weariness and decreased energy of the body, mental fatigue refers to the feeling of tiredness experienced after long periods of cognitive activity (Boksem & Tops, 2008; Pigeon et al., 2003).

There are currently multiple definitions of fatigue for children based on those developed for the adult population. Depending on the definition of fatigue, prevalence rates in children range from 1.29% to 2.34% (Farmer et al., 2004). Children experiencing chronic disabling fatigue but who do not fit the narrow criteria for CFS nonetheless experience significant fatigue-related impairment (Fowler et al., 2005).

Current definitions of fatigue are varied and based on presentations of fatigue in adults, highlighting the issues associated with applying these definitions of fatigue in research and clinical diagnosis in children. Despite difficulties in defining and identifying fatigue in children, there is growing research into associated causes and outcomes.

1.2.1 Conditions and Circumstances Associated With Fatigue

Many factors can result in fatigue amongst children in 'every-day' life, from sporting events, busy school and extra-curricular schedules, to lifestyle factors such as poor diet and

low levels of physical activity (Ho et al., 2019; Maher et al., 2015; Steenbruggen et al., 2015).

Fatigue may be related to an existing and sometimes undiagnosed illness or condition. Children may experience ongoing fatigue as a symptom of chronic or terminal illnesses including cancer, multiple sclerosis, fibromyalgia or rheumatic diseases (Varni et al., 2002; Varni et al., 2004; Yeh, 2016; Zafar et al., 2012). Whether fatigue may be related to the disease or condition itself or to the treatment, it can be one of the most impactful symptoms of chronic illness in children (Ho et al., 2019). Children with physical disabilities experience higher levels of fatigue, similar to those experienced by children with cancer, when compared to normally developing children (Maher et al., 2015).

While CFS is less understood in children than adults, it still places significant burden amongst the pediatric population (Gregorowski et al., 2019). Children with CFS experience sleep problems including sleep disturbances, difficulty falling asleep, unusual sleep patterns, and unrefreshing sleep (Brigden et al., 2017; Collin et al., 2018; Snodgrass et al., 2015). Prevalence rates of CFS in children vary in reports from 0.22% to 1.35% (Lim et al., 2020). However, concern has arisen around the problem of misdiagnosis given the many definitions and criteria for CFS in use in both research and practical settings (Geraghty & Adeniji, 2018).

1.2.2 Impacts of Fatigue on Children's Wellbeing and Development

Like sleepy children, fatigued children experience negative impacts which affect many aspects of life. Children with CFS experience anxiety, stress, and depression, which can be expressed as frustration and irritability (Crawley et al., 2009; Haig-Ferguson et al., 2009; Parslow et al., 2017). A review of qualitative studies by Parslow et al. (2017) of children's experiences of CFS reported themes of emotional vulnerability and uncertainty, describing irritability, sadness, worry, anxiety, and experience mental health issues and negative mood. Children with CFS experience difficulty with focused and sustained attention, memory and

recall. This can manifest through difficulties in attending to conversation or instructions or remembering things they have learnt or where they left something (Haig-Ferguson et al., 2009). This decline in cognitive ability as a consequence of fatigue can greatly affect children's behaviour. The stress experienced by children with CFS can be expressed through behaviours which exhibit irritability, such as fidgeting or giving up on the task at hand. (Haig-Ferguson et al., 2009). Fatigue also has the potential to affect children's performance at school, and is reported as the most common reason for school absence (Crawley et al., 2011; Varni et al., 2004).

1.3 Distinguishing Between Sleepiness and Fatigue in Children

1.3.1 Issues and Importance of Precise Diagnosis

Sleepiness and fatigue, while distinct phenomena, have causes and outcomes which often overlap, highlighting both the difficulty and importance of correct and efficient diagnosis and implementation of effective treatments. There are many factors which may inhibit this process in a clinical setting. For example, the accurate identification of symptoms is complicated by the fact that children may not present with typical sleepy behaviour on initial clinical impression, which increases the risk for a misdiagnosis such as for ADHD (Dahl, 1996; Golan et al., 2004). Similarly, children with CFS may present differently to their adult counterparts, reporting less post-exertional malaise, which could potentially confuse the diagnosis of CFS (Crawley, 2017). In recent qualitative studies on CFS, children discussed experiences of negative medical encounters including delays in diagnosis, misdiagnoses, and unsupportive and disbelieving interactions with doctors (Ali et al., 2019; Parslow et al., 2017). Furthermore, before a child may be examined by a doctor, it is necessary that parents recognise a problem. However, sleep problems are significantly underreported by parents in general practice consultations in Australia despite a relatively high frequency of sleep

problems in children (Blunden et al., 2004). As sleep problems can be related to sleepiness or fatigue, this is a significant barrier to diagnosis and treatment.

Adult misunderstandings of sleepiness and fatigue in children are detrimental to healthy development and wellbeing. Unfortunately, these misunderstandings present in, and constitute a limitation, of the current measures used to assess sleepiness and fatigue in children. Such limitations include adaption from adult measures, reliance on parent reporting of symptoms, lack of validation for children under 12 years, and the inability to distinguish between sleepiness and fatigue.

1.3.2 Limitations of Current Measures of Sleepiness and Fatigue

According to a review by Fallone et al. (2002) sleepiness can be defined in three measurable ways. First, physiologically, the objective tendency to fall asleep. Second, behaviourally, where adults can observe children's responses to feeling sleepy. Third, psychologically, where children can describe the feeling of being sleepy in terms of physical feeling, mental and emotional feelings.

The gold standard objective measurement of daytime sleepiness for children over 5 years is the Multiple Sleep Latency Test (MSLT) (Hoban & Chervin, 2001; Moreira & Pradella-Hallinan, 2017). The MSLT measures the time it takes to fall asleep in various daytime napping circumstances (Hoban & Chervin, 2001). Shorter sleep onset latency indicates a higher level of physiological sleepiness (Fallone et al., 2002). However, the MSLT is time-consuming, expensive, and laborious and must be performed only after an overnight polysomnography (PSG) (Fallone et al., 2002; Shen et al., 2006). The PSG, the gold standard objective measurement of sleep, records sleep onset, duration, and architecture in a laboratory setting, requiring overnight observation (Hoban & Chervin, 2001). As a single testing point, the MSLT can be affected by a child's mood, their level of activity, their level of understanding and cooperation of the test instructions, especially children exhibiting

hyperactive behaviour (Hoban & Chervin, 2001). Most importantly, results of the MSLT do not always correlate with the most widely-used subjective sleepiness scales (Johns, 2000).

Subjective scales measuring sleepiness are cheaper, more efficient and accessible than the MSLT. However, there exist limitations in the ways subjective measures are developed and designed. Some sleepiness measures are adapted from adult measures and have been partially altered for use with children. However, measures which capture sleepiness in adults may not be able to detect the same symptom in the pediatric population, due to the typical hyperactive and inattentive presentation of sleepy children (Bioulac et al., 2020; Dahl, 1996; Moreira & Pradella-Hallinan, 2017). The Epworth Sleepiness Scale adapted for children and adolescents (ESS-CHAD) is a self-report questionnaire adapted from the widely-used Epworth Sleepiness Scale (ESS) for adults, which measures the likelihood of falling asleep in various daytime situations (Johns, 1991). A recent review found that the ESS-CHAD and other modified versions of the ESS for children are the most frequently used measures of EDS in pediatric populations (Benmedjahed et al., 2017). Nonetheless, these ESS-modified versions only alter the wording of some items, for example, in one item, a reference to alcohol was removed and replaced with a reference to eating lunch quietly by oneself. (Melendres et al., 2004). As children tend to have a hyperactive response to feeling sleepy, they may not report the tendency to fall asleep in the given situations. The ESS-CHAD has been validated for use with adolescents, but is yet to be validated for use with children under 12 (Janssen et al., 2017).

Other self-report questionnaires have been developed to measure sleepiness in children, like the Pediatric Daytime Sleepiness Scale (PDSS) (Drake et al., 2003) and the Cleveland Adolescent Sleepiness Questionnaire (CASQ) (Spilsbury et al., 2007). The PDSS measures sleepiness and other variables related to sleepiness in middle school children aged 11 years and above. Questions related to sleepiness were developed through research with

children and adults involving situations that may be sensitive to sleep loss (Drake et al., 2003). The CASQ is similarly designed for children 11 years and above and was developed based on research and review of other sleepiness measures (Spilsbury et al., 2007). Like the ESS-CHAD, it measures levels of sleepiness through subjective likelihood of falling asleep in different situations (Drake et al., 2003; Moreira & Pradella-Hallinan, 2017).

Other subjective measures are designed to rely on the observations of parents or teachers to determine the level of sleepiness a child may be experiencing. The Teacher's Daytime Sleepiness Questionnaire (TDSQ) is a teacher-report scale which assesses typical sleepy behaviours children aged 4-11 are likely to exhibit in a classroom (Bioulac et al., 2020; Lewandowski et al., 2011). The items, based on clinical experience and literature review, include rating frequency of behaviours such as yawning, difficulty staying awake, and complaining about sleep (Owens et al., 1999). The Children's Sleep Habits Questionnaire (CSHQ) (Hoban & Chervin, 2001; Owens et al., 2000), the Sleep Disturbances Scale for Children (SDSC) (Bruni et al., 1996; Marriner et al., 2017), and the Sleep Disorder Inventory for children and adolescents (Moreira & Pradella-Hallinan, 2017), are all parent reported measures of sleep related disorders with sections relating specifically to sleepiness. The limitation of measures which only seek parental observation is the potential to miss important subjective feelings of sleepiness a child experiences. Paavonen et al. (2000) found one-third of all potential cases may go unnoticed when only obtaining parental reports of sleep problems, and that 95% of severe sleep problems were only reported by the child.

There is no objective measure of fatigue in common use, but many subjective scales exist for adults, and a small number of these are used with children. The most commonly used measure is the Chalder Fatigue Scale that was originally developed for use with adults but has been used to assess fatigue in adolescents without undergoing any alteration, and without validation for use with children (Chalder et al., 1993; Kawatani et al., 2011; Patel et

al., 2003). The Pediatric Quality of Life (PedsQL) Multidimensional Fatigue Scale (MFS) measures levels of fatigue in pediatric patients and healthy children aged 2 to 18 years. It involves child and parent-proxy parallel reports of fatigue and has been demonstrated as a reliable and valid tool (Varni et al., 2002; Varni et al., 2004). However, the PedsQL MFS does not differentiate fatigue from overlapping symptoms of sleepiness. The Childhood Fatigue Scale was developed to measure fatigue in pediatric oncology patients, aged 7 to 12 years. Items were developed from focus group interviews and reviewed by pediatric oncology clinicians, with the generalisability beyond this group unclear (Hockenberry et al., 2003).

The limitations of existing subjective measures of sleepiness or fatigue in children can be summarised as: 1) being adapted from adult measures, 2) reliance on parent-reporting of symptoms, 3) lack validation with children under 11 years of age, and most importantly, 4) they do not distinguish between sleepiness and fatigue.

1.3.3 Suggestions for Future Measures

In a recent study by Ludwig et al. (2019b) children were given six sleep related words to define including "sleepy" and "tired". Most children were able to give 'suitable' definitions for these words (84% and 75% respectively) but found other words like "drowsy", and "alert" more difficult to define. The authors suggested that current sleep surveys for children may not yield accurate results due to lack of comprehension.

Considering the significant discrepancies between parent and child reported sleep problems, it has been suggested that child self-reports be used to supplement parent reporting. Children are able to reliably report different somatic and psychiatric symptoms when the methods for gathering this information is developmentally appropriate for their age (Paavonen et al., 2000). However, the targeted investigation of language that validly and reliably identifies and distinguishes sleepiness and fatigue from a child's perspective remains a gap in the literature.

1.4 Current Study

The current research into sleepiness and fatigue in children and the measures used to assess these phenomena in children demonstrates a dearth of understanding of the child's perspective of these subjective symptoms. Such an understanding is required to develop a valid self-report measure which can distinguish between sleepiness and fatigue in children. To address this gap, this study is the first to examine how children talk about, and distinguish between, sleepiness and fatigue.

Chapter 2: Methods

2.1 Participants

Participants (N= 42) were children in grades three, five, and seven attending primary school in South Australia. See Table 1 for participant demographics. Children who were taking medications, did not speak English as their first language, or were diagnosed with a medical or psychiatric disorder were excluded from the study. A purposive sampling method was employed to aim for richness rather than representativeness of data in line with qualitative methods. Children were recruited from several different schools in an attempt to provide an inclusive coverage of socio-economic status.

Table 1Participant Demographic Information

Participants	Gender	School SES
	Grade 3	
Elijah	Male	3
Daisy	Female	2
Henry	Male	2
Matilda	Female	2
Lachlan	Male	6
Sam	Male	2
Alice	Female	2
Kate	Female	3
Adam	Male	2
Clare	Female	6
Caleb	Male	7
Rose	Female	7
Sienna	Female	2
Lucy	Female	6
Alexander	Male	2
James	Male	6
	Grade 5	
Darcy	Female	7
Oscar	Male	7
Catherine	Female	2
Grace	Female	2
Scarlett	Female	2
Sarah	Female	2
Annabel	Female	2
Lily	Female	6
Christian	Male	6
Leo	Male	1
Noah	Male	2

Participants	Gender	School SES
Xavier	Male	6
Charlie	Male	6
Amelia	Female	6
	Grade 7	
Ella	Female	1
Eloise	Female	6
Phoebe	Female	6
Ethan	Male	7
William	Male	2
Benjamin	Male	6
Hannah	Female	6
Theodore	Male	7
Jemima	Female	7
George	Male	2
Joseph	Male	6
Daniel	Male	2

Note. All participant names are pseudonyms

2.2 Procedure

Ethics approval was obtained from the Human Research Ethics Committee of the Women's and Children's Health Network and the University of Adelaide. The data were previously collected for a project commenced by a PhD student, but the project was terminated before analysis was completed.

Twenty-eight schools were invited to participate in the study. Parental consent forms and information packages were distributed to children at participating schools. Consent for children to participate in the study was received from parents. Participants agreed to being interviewed and audio recorded.

Forty-two interviews were conducted face-to-face during school hours. Interviews lasted between 8 and 40 minutes in duration. Data saturation occurred at the 32nd interview, however, as all remaining interviews were organised, they went ahead as scheduled.

As the aim of the study was to elicit and analyse children's language in regard to specific concepts, the data were collected using a controlled method. A semi-structured interview format was adopted as its flexibility elicits specific questions related to the research topic, whilst allowing participants to elaborate on their responses (Liamputtong, 2020). Questions were asked at different times within the interview in order to foster rapport and participant ease, thus promoting a more detailed response.

2.3 Materials

The semi-structured interviews employed eight vignettes in the form of four visual (illustrations) and four audio scenarios (stories) (Appendix A). The use of such scenarios encourage children to feel they have some control in the interview setting, allowing them to respond freely and introduce personal experiences as they wish (Barter & Renold, 2000). Scenarios were based upon three concepts central to the research topic; sleepiness (including sleep deprivation and disruption), mental fatigue, and physical fatigue. The visual scenarios

included a mix of male and female characters and the audio scenarios depicted either Jack (presented for boys) or Emma (presented for girls).

2.4 Analysis

Data were analysed using Thematic Analysis (TA), which involves "identifying, analysing, and reporting patterns (themes) within data" (Braun & Clarke, 2006, p. 79). The software program NVivo 12 (released in March, 2020) was used to facilitate data coding.

The data were originally collected with the aim to potentially inform future approaches to assessment of sleepiness and fatigue in children. More specifically, the development of a subjective self-report tool to measure sleepiness and fatigue in children, which uses language and terminology used by children. Considering this, a realist approach was adopted, which stipulates that meaning and experience is reflected in a straightforward way through language (Braun & Clarke, 2006). For similar reasons, the data were analysed on the semantic level, in which themes are found in the explicit meanings of the language without looking for or interpreting any deeper meaning (Braun & Clarke, 2006). Finally, inductive analysis, considered to be "data-driven" where the themes identified are linked to the data, was employed to code and search for themes (Braun & Clarke, 2006, p. 83).

To ensure transparency of the research, an audit trail was kept throughout to record any possible themes, research ideas, and processes (Tracy, 2010). To reduce the impact of individual bias on the results, a sample of the interviews and definitions of codes were provided to an independent researcher to complete. Both researcher's coding of that sample was compared for similarity and agreement was found for the majority of the sample. Where differences were identified, both researchers discussed and came to agreement.

Analysis followed the steps outlined by Braun and Clarke (2006, p. 87). As the interviews had already been transcribed, familiarisation with the data was achieved by listening to all interview audio-recordings while reading transcripts to confirm that the

recordings matched the transcripts. The transcripts were re-read another time before coding and notes were taken throughout to record initial thoughts.

Initial coding commenced with consideration of the coding system previously created by the aforementioned PhD student, but was amended according to the interpretation of the current researcher. Interviews were coded systematically first according to the gender, grade level, socio-economic ranking of the school attended by the participant; modality of scenarios, specifically whether responses were in relation to audio or visual scenarios; and, the concepts targeted by scenarios (sleepiness, mental, or physical fatigue) as well as each individual scenario. This was followed by specific coding based on analysis of the language used across the interviews. This involved coding according to the manifestations of sleepiness or fatigue children talked about (behavioural, physical, social, emotional, mental), including language describing the opposite of sleepiness and fatigue, namely wakefulness. Responses on this level were also coded according to language children used to describe any differences or similarities between the concepts of sleepiness, mental, and physical fatigue.

Chapter 3: Results

Analysis of the data resulted in the identification of two overarching themes: 1) language that describes 'objective' experiences of sleepiness and fatigue (that is, experiences that could be observed by others) and 2) language that describes 'subjective' experiences of sleepiness and fatigue (that is, internal experiences which cannot be observed by others). Within these broad themes, four subthemes exist: 1) behavioural 'causes', 2) 'behavioural responses', 3) 'body-based sensations', and 4) 'mind-based experiences' respectively. These themes will be discussed in detail below.

Within each theme, responses to the concepts of sleepiness, mental, and physical fatigue are separated and compared. The responses discussed under each concept correspond to the respective visual or audio scenarios listed in Appendix A.

3.1 Objective Descriptions

This theme includes children's language which describes observable behaviours, including causes and responses to sleepiness or fatigue.

3.1.1 Cause

In this subtheme, children talked about the differing causes, usually behavioural, which lead to either sleepiness, mental or physical fatigue.

Sleepiness.

The most common explanation of sleepiness was simply lack of sleep, usually accompanied by a reason for that lack, for example, being social, "watching a TV show" or doing "homework" (Ethan). The first quote below relates to visual scenario one.

She might have not got enough sleep during the night, or probably didn't go to bed early enough. (Annabel)

Sometimes I might have people over, sometimes I might not be able to get to sleep because sometimes when I get into bed I'm really tired but then I don't get to sleep. (Clare)

Mental Fatigue.

Children were asked why the character in audio scenario four, did not want to attend their piano lesson after a week of tests. Here, mental fatigue was attributed to doing "lots of work" (Caleb) or doing the same type of cognitive task for long periods of time.

Probably because she's had all those tests during the day and she doesn't want to go do the piano lesson because it might feel like more work on top of what she's done during the day. (Phoebe)

As a further example, the size and difficulty of the puzzle in visual scenario four was perceived as requiring a high level of sustained attention and problem solving, resulting in mental fatigue. From here, and throughout, fatigue (both mental and physical) are referred to by children as 'tired'. However, this claim of tiredness is inferred as mental fatigue due to the nature of the task.

She's probably feeling tired because she has to do the big puzzle. (Scarlett)

It's a hard puzzle and she's tired because she's been doing it so long. She's looking down, maybe getting a bit bored. (Caleb)

Physical Fatigue.

Children talked about being fatigued after doing anything requiring physical exertion in excess or for long periods of time, for example, "because he ran heaps" (Alexander).

Well, Emma was probably tired because she'd been running all day. When it was our sports day, we didn't win but we were still very tired, and we couldn't move because we'd been doing heaps of activities. (Hannah)

It's Santa Claus at Christmas time and he looks tired because he's got so much presents to deliver and he can't do them all. (Christian)

Sometimes, the cause of fatigue was identified as being unprepared physically for exercise, perhaps through not keeping fit generally or not warming up specifically.

Because maybe she had participated in a lot of races and a lot of things, so that would have made her legs work a lot and maybe she might not have been very fit, we don't know. (Darcy)

Someone who might have not done enough exercise or gotten outside for a run for something has stopped running before the other kids. And the other kids are still going because they run outside or they go shoot some goals or something. (Eloise)

The causes of sleepiness and fatigue outlined above were reflected in the answers children shared when asked directly whether there were differences between the two concepts. Here, children articulated what they saw as the main causal differences between sleepiness and fatigue, which were that sleepiness followed lack of sleep, and fatigue followed too much activity.

Because sleepy is because you didn't get enough sleep, and tired is after doing something and you just can't do anything else because you've done something too much. (Oscar)

However, physical activity, such as running, was related to physical fatigue, whereas cognitive tasks such as school work resulted in mental fatigue. The example below contrasts visual scenario four, where a girl attempts a puzzle, against visual scenario three which depicts a boy running.

Because she's probably fed up and he's probably – he's been doing like active and she's been sitting down and doing something, but he's been running and stuff. (Clare)

3.1.2 Behavioural Response

Language in this subtheme describes the behavioural responses children identified as occurring as a result of feeling either sleepy or fatigued. The time of day when behaviours occurred was indicative of either sleepiness or fatigue. Sleepiness influenced behaviour mostly in the morning, during typical breakfast routines, and during the day at school; behaviours related to fatigue began later in the day and were more closely associated with the activity causing the fatigue.

Sleepiness.

Children often shared that they struggled to get out of bed, saying they "pretty much get forced out of bed" (Benjamin) in the morning when they stayed up late the night before.

Parents were typically involved in trying to get the child out of bed and to school.

Sometimes she [mum] calls me about 20 times and then she ends up yelling at me.

Like in the morning, when I have to get up to school. Because sometimes I stay up to 8:30. But once a week, I stay up to 9:30. If I don't get up in the morning, my mum ends up yelling at me. Then my dad comes in and pulls my blanket off of me.

(Catherine)

When children were out of bed, sleepiness was associated with lack of motivation or desire to participate in daily routines and preferring "to go back to bed and sleep" (Ethan).

I might be tired and I don't feel like getting up and I want to stay in bed and just rest...

I don't feel like getting up and walking around. (Clare)

I think she wouldn't want to do her school work. She wouldn't want to do anything.

She wouldn't want to run or play... No, she would just like to fall asleep. (Darcy)

At other times, children spoke of doing the "normal things" expected of them, but that they felt "a bit tired" (Caleb).

I kind of move more slowly. Like normally I get up and I move really fast and get ready for school. I probably walk a bit slower. (Amelia)

When I'm really tired my head just sort of drops down if I'm walking around. Your legs are dragging, you sort of drag yourself. (Benjamin)

Often, children talked about eating breakfast as being "probably the hardest thing to do" (Xavier) when sleepy. Children described not wanting to eat in the morning or "just eating really slow and almost falling asleep" (Daniel).

Sometimes in animations they pull their head down into their breakfast or they might not want to eat. They might feel sleepy when they're eating breakfast.

(Lucy)

Once children were at school, they often talked about displaying inattentive behaviours in the classroom when sleepy. They were often aware that this behaviour was observable by others, particularly by the teacher, and could result in negative consequences.

Yeah, maybe because she might not be listening to the teacher and she might be acting a bit weird and like she doesn't want to be at school that day... Like not listening, ignoring everybody when they're trying to tell her something, and like not listening... and not like doing anything and refusing to do their work or something. (Alice)

She won't be focused. She won't listen. Then she'll probably - when she's doing work and she doesn't listen she could get in trouble and stuff. (Hannah)

More specifically, children described the adoption of a specific posture, for example, "I put my head on the table" (Catherine) or leaning their head on their hand. This behaviour was described as being an identifiable feature of looking 'tired'.

By putting your hands all over your face and just going like that a lot, that's a really tired gesture. It's like really common... Yeah, because like when you're tired you can hardly keep your head up, like I say. So that's why you put your hands on there, because it kind of keeps it up. (Benjamin)

Yeah, because he will sit down and he'll, sometimes, almost fall asleep or he'll be really tired sitting there, doing – like just leaning his arm on the table with his head on his arm yawning and stuff like that. (Noah)

When discussing the social implications of sleepiness, children often spoke about not wanting to participate in usual play, saying they were "too tired to run around" (Alexander). They also talked about being "quiet" (Ethan) or "dull" and not wanting to "talk and laugh" (Jemima) when sleepy.

Not having enough sleep might affect a bit on that because you don't want to play. You just want to sit and eat your recess or lunch... Like you might just sit there and eat your recess and lunch and not want to go out and play with all your friends. (Alice)

She might walk slow and the other ones will be in front of her and then they'll say hurry up and all that to go to school... She'll play with her friends but she wouldn't play properly because her arms will be all weak and she'll want to go to sleep. She'll be so tired that when she throws [a ball] she'll throw a little throw... She would throw a little throw, like for netball because I do netball. (Sarah)

Mental Fatigue.

In comparison to sleepiness requiring sleep, the most common behavioural response to mental fatigue was to "sit down and have a rest" (Alice) or "relax" (Matilda). Children also shared that they did not wish to do any task requiring concentration or attention.

At the end of the day he'll be wanting to just relax. Do something that's not involving really doing a lot with his head. Maybe just sleeping. Something calm... Yeah after I've had a really big day with maths tests and stuff I like to come home and have half an hour's rest and then I do my work that I have to do. (Theodore)

It feels like you just want to lie down anywhere, like on a couch, or a chair, or a bed, anything that's comfortable. (Joseph)

When completing a task that required sustained attention for long periods of time, children sometimes talked about distracting themselves or wanting to "do something different" (Clare).

I don't know, NAPLAN - I just fiddle with them. It's kind kept me sort of not going mental. (Benjamin)

I feel like I don't want to do any more tests, but I feel from sitting there in the quiet I would like to go out and be able to play... (Darcy)

Additionally, children sometimes described tasks taking longer to complete when they felt fatigued.

I wasn't really ready for that one. I was really tired. I couldn't concentrate. We have lots of maths tests in our room. It takes me a long time. Something that would have taken me like half an hour takes me from the start of the day until after recess.

(Theodore)

Physical Fatigue.

As in children's language about mental fatigue, physical fatigue was also associated with the response of wanting rest or relaxation. The difference between physical and mental fatigue in this respect was the cause of fatigue rather than the similar behavioural response. Children talked about wanting "to have a big, big, big rest" (Henry) or wanting "to go to sleep" (Elijah). Additionally, though talk of wanting to go to sleep was associated with both sleepiness and physical fatigue, what distinguished these cues were cause or time of day. Sleepiness was associated with the want to sleep in the morning after not having enough sleep or during the school day, whereas physical fatigue was associated with the want to sleep after physical exertion, usually at the end of the day.

Because she did all the sports. She's so exhausted that she just wants to rest. (Sarah)

When I got home, I pretty much had a drink and went straight to sleep. So sleep's the only remedy [to overexertion]. (Benjamin)

Children talked about not wanting to or being unable to participate in extra physical activity or wanting to "give up" (Hannah) when feeling physically fatigued. Some stated that being physically fatigued impaired their performance, for example, "I can't run as fast" (Caleb). This was also similar to the behavioural responses of mental fatigue, however, the type of activity which preceded the fatigue was the distinguishable cue; where mental fatigue follows cognitive tasks, physical fatigue follows physical exertion.

[I felt] really tired and like I didn't want to do much stuff... but I managed to walk back to the classroom but I didn't want to help clean up or stack the chairs or anything... because I was tired and all my body had been working lots that day and it didn't want to do much more but rest. (Alice)

When children were directly asked about the difference between being sleepy or fatigued, they simply summarised the difference in behavioural responses.

When you're sleepy you want to go to sleep. When you're tired you just want to relax.

(Lachlan)

3.2 Subjective Descriptions

Within this theme, children talked about the subjective experiences associated with sleepiness and fatigue, and specifically about cues that were only available to them. When prompted to talk about the body and mind in relation to sleepiness and fatigue, children consistently attributed agency to (or personified) specific body parts or organs. For example, the body is "not wanting to move yet" (William) and the legs "don't want to walk" (Lachlan).

3.2.1 Body-Based Sensations

Within this subtheme, children talked about the physical sensations within the body which accompanied sleepiness and fatigue. The location of any given physical sensation was the most distinguishing feature between sleepiness and types of fatigue.

Sleepiness.

When children were asked how they might feel proceeding insufficient sleep, the typical response was simply that they would feel sleepy. However, they often elaborated on this response by detailing physical sensations associated with sleepiness. Most children talked about their eyes, some reporting having sleep or "the little green hard bits in my eye" (Daisy) when sleepy in the morning; or other sensations such as "I blink more often" (Eloise), "[my eyes] hurt when I'm tired" (Clare) experiencing blurry vision and eyes feeling "heavier than normal" (Darcy).

Her eyes would feel like - sometimes they would go a bit blurry when you look down or something. Be a bit blurry. You'd probably get a headache if you're looking at lots of words when you're tired. (Annabel)

Very heavy... They [eyes] feel like I dropped a brick on my toe... They feel like they're holding a brick up. (Sam)

Children also often talked about the eyes needing or wanting to close, sometimes involuntarily.

When it's tired you want, sometimes you want your eyes want to just stay open but they just kind of shut slowly and you can't keep them open and you just want to lie down and have a rest. (Christian)

In addition, children often talked about various sensations in their heads when sleepy, which included "headaches" (Clare) and pain as well as other sensations like 'dizziness'.

A bit painful... It's like it's throbbing... Yeah, it feels like it's trying to push my skull out of place. (Sam)

Dizzy... I feel like I'm just going to fall asleep while I'm standing up.
(Kate)

A particularly unique feature of sleepiness was a weak feeling or numbness in the body when children first woke up. Legs or arms were "sleepy" (Adam) and children were not able to "move them properly" (Daisy).

I can't really lift much up. My hands are like I can't clench my fist and that's just like all that, because if I want to touch and try to grab things it sort of hurts and has this really weird feeling. It's like a numbness but it's kind of like really annoys you when you put your fists together and then you have to pry it apart because there's really weird feeling that just makes you do that. (Benjamin)

The body, generally, was described as feeling "not so good" (Kate), lacking "energy" (George), and "not really feeling in the zone" (Benjamin).

They just feel flat and you can't really do anything...It means you're really tired. You can't really do anything and you just feel weak... Sometimes weak. Sometimes just a little bit shaky and all that. (Daisy)

As I was saying before he'd just be very, very, very tired and he just wouldn't want to wake up. He'd just want to go back to sleep... He won't be as energetic. (Xavier)

More specifically, the arms and legs were "floppy" (Sienna), "dangly" (Xavier), "droopy" (Hannah), "lazy" (Catherine), or simply "asleep" (Sarah). Some children spoke of pain, but less so than in responses to mental and physical fatigue.

He's going to feel really tired and he's not going to feel very good and healthy, because he stayed up too late... His body is going to be really heavy and he won't be able to hold up any of his weight. He won't be able to do any of that stuff, like running around or anything, because his legs will be all tired and his joints will hurt... When he goes to school he probably won't be able to do much of all his work because he will be hurting too much and he might feel sick too. (Noah)

Mental Fatigue.

When children were asked to talk about physical sensations in relation to fatigue, initial responses described feeling tired, followed by elaborations on the associated bodily sensations meant by tiredness. As in talk regarding bodily sensations when sleepy, mental fatigue was often associated with the eyes and head. However, the distinguishing feature from sleepiness was that mental fatigue was due to consistent use of these body parts during a cognitive task. Children talked about their eyes shutting involuntarily, for example, "my eyes start closing and start shutting themselves" (Leo). They also talked about their eyes feeling "sore" (Rose), and that their vision became "blurry" (Annabel) because "they'd been open for so long, looking at the pages" (Catherine).

A bit of reaction, how you get like something in your eye, but it isn't and you do that...

Yes, twitch your eyes. (Joseph)

When I've been doing my computer, on the computer. I've been looking at it for too long and then my eyes just go all fuzzy. (James)

Painful or unpleasant bodily sensations were described in relation to the head. Again, the difference from talk of the head associated with sleepiness, is in the cause of sensation. These descriptions involved feeling "dizzy because I'd been thinking heaps" (Alice) or having headaches, which were attributed to "working too hard" (James) or "doing [work] for a long time" (Adam).

It felt really – it felt tired and it felt like a balloon... it felt really light... like you can't think. It just feels like it's got full of air...it's only happened to me once when I was doing lots and lots and lots of work in the NAPLAN test. I did it once and then I kept rubbing it out and doing it, because I couldn't think what it was... (Noah)

It feels like it's going to blow... it's like it's throbbing but only that much harder.

(Sam)

Children talked about pain in relation to the use of specific body parts, for example, their "hands would be quite sore from writing a lot" (Darcy) or "writing for so long" (Alice). The neck was described as "a bit sore... from looking down at the puzzle" (Amelia) and the "back hurt too, because I don't write sitting up straight" (Alice). In contrast, they also talked about disuse of their bodies resulting in particular sensations such as feeling numb or stiff and needing to move or stretch.

Because of all the hard time and staying still and stuff, because when you stay still your bones get stiff... When you go out of the classroom for recess here, you just can't - you have to stretch out your muscles and stuff if they're really cramped. (James)

Physical Fatigue.

The most common response children shared when asked about the feelings associated with physical exertion was "sore and tired" (Alice). The head and eyes were not a focal point of discussion compared to talk about sleepiness and mental fatigue, rather the emphasis was on the body generally, including the arms, legs, and chest. Children identified physical fatigue when their bodies would "start to hurt" (Adam). Language about pain was related to specific body parts such as, "my bones were tired...because whenever I moved my arms and legs ached" (Charlie), "[my] arms were sore from moving when I was running" (Alexander) and "[my] legs would get all sore and tired" (Clare). Children sometimes talked about the general feeling of the body feeling "overworked" (Amelia), the feeling of being "out of energy" (Annabel), and just generally "exhausted" (Caleb).

When my legs get tired, my feet and that get sore. It travels all through my body... it gets through the arches in my feet, through to my head. (Annabel)

In the long run, I came 10th or something for year six, seven. I felt really drowsy and I felt like I couldn't move... it's almost like when you're walking, it's almost like you're about to fall down and dehydration and sleepiness at the same time, and just fall down and go to sleep. (Benjamin)

Children talked about neutral or unpleasant sensations associated with feeling fatigued, other than pain. Legs and arms could feel "wobbly" (Catherine), "droopy" (Caleb), "want to drop" (James), or were "stressed out" (Hannah).

Felt very tired. Felt hungry. A lot more thirsty. Sweatier. (Annabel)

It feels like that your arms can't lift anything; they feel they just don't have any energy in them. Like, if the blood cells are not in there. Like how the blood goes into your body system, if it feels like that there's none going in your arms, it feels numb.

(Joseph)

The feeling of being "puffed out" (James), "breathing quite hard" (Darcy) and feeling pain in the chest was a prevalent and unique response related to language about physical fatigue. The chest was described as "sore" (Kate) and "phlegmy" (Benjamin). The heart was described as "pumping" (Ethan) and "beating really fast" (Daisy).

It might hurt a bit after you run a long distance. Sometimes your chest hurts after a long - if you've been running really fast for a long distance your chest might hurt a little bit. (Clare)

He's puffed out because he's run too fast and stuff... you have to stop and breathe, otherwise you will die. Sort of fall to the ground. (Alexander)

When describing the head, sometimes children would talk about feeling "dizzy" (Catherine) or having a "headache" (George). This was a common feature across the three concepts, however, fewer children mentioned the head and eyes in relation to physical fatigue than sleepiness and mental fatigue.

Probably like dizzy... from going around to all the houses and stuff... it's sort of like a headache and you can't really - it hurts when you think and stuff. (Hannah)

Just a bit dizzy... because it's - he's had to run around a lot and look at all the different places... your head's just like spinning. It's not really spinning, it's just inside you think it's spinning. (James)

Few children mentioned sensations associated with the eyes, such as soreness, twitching, or heaviness.

Maybe he couldn't look properly. Maybe he'll be a bit fuzzy... it's like you have to twitch your eyes to see properly. (Grace)

Just tired of having to use all their muscles to keep the eyelids up, they just want to close. (James)

The responses within this subtheme showed a pattern of relating sleepiness and mental fatigue to the eyes and head, while physical fatigue was more often associated with the body generally and more frequent descriptions of pain. The location in the body of pain or unpleasant sensations, time of day, and the preceding activity all differentiate one phenomenon from another where there are some similarities in description. This is reflected when children were asked directly whether they thought a difference between sleepiness and fatigue existed.

Because usually when you're sleepy it's more like your eyes hurt and your head and stuff but when you're tired it's all your body. (Jemima)

Here, the sensation of being puffed out related to physical fatigue is contrasted against the need to sleep associated with sleepiness.

Really different [sleepy and tired]. Because when you're exhausted you need to puff and breathe but when you're sleepy you just need to fall asleep to get your mind off all then start getting smart and learn. (Sarah)

Even though 'tired' was common to many descriptions, mental fatigue could be related to the brain, while physical fatigue was related to the body generally, including arms and legs. Here, the comparison is made between the girl sleeping in class in visual scenario one and the boy running in visual scenario two.

Her brain's like tired and his legs are tired and his arms are a bit tired. (Elijah)

3.2.2 Mind-Based Experiences

This subtheme encompasses children's language about subjective emotional or cognitive experiences associated with sleepiness and fatigue.

Sleepiness.

When discussing sleepiness, children talked about the inability or struggle to 'think' at school, which affected their academic performance. They were asked about how sleepiness would affect the head or brain in relation to themselves or the characters presented in the scenarios. They described their head as "sleepy" (Daisy), "tired" (Elijah), that they "can't think" (Eloise), and that the brain was "shut off" (Xavier).

A bit not really switched on [the brain] ... you can't really think about stuff. You kind of like just do stuff. Like if you're doing maths you just do it. You don't really care if you get it right or wrong. (Amelia)

She might not be able to think for a while or she'll just be a little bit tired... it's annoying because you probably know the answers but you can't think about it or solve the answers. (Eloise)

As a further example, children shared that it was "hard to concentrate" (Jemima), that they were "confused" (Sarah), and that they were "not thinking straight" (Daniel) when sleepy.

He's going to be tired and everything's going to be kind of hard to understand. It's going to be like that Sultana Bran ad where everything's fuzzy...He's going to be like fuzzy. (Theodore)

He'll probably be like this in class and he'll probably still do his work and he'll be trying to focus but he'll be missing all these little steps to everything... he will be

focusing as much as he can but he'll miss just little parts. Like one second he'll drowse off and then he would have missed something and then it would all add up. Then he'd think he'd missed everything. (Benjamin)

Children often talked about feeling grumpy or angry from not getting enough sleep. They commonly mentioned that they would feel "grumpy, cranky, [or] ... angry" (Will) with "anyone really" (Adam), which lead to blaming things on "other people but it's not their fault" (Matilda).

I usually can't control my anger...I go a bit psycho...I don't actually know because I can't actually control myself, so yeah. (Sam)

She might have stayed up really late and the next day she might have been very grumpy, not wanting to do anything at school... it's frustrating and you kind of blame it on everybody else. (Lucy)

Children's talk about grumpiness and the accompanying behaviour was rarely separate from the social implications of it. Although children talked about a behavioural response to sleepiness, grumpiness, anger or irritation were typically implicated.

She could be aggro...like very yell-ive. Like yelling a lot and saying, I don't want to do this. Saying rude comments and things like that. (Annabel)

I know how it feels because one day I had a sleepover at my friend Erin's place and I couldn't get to sleep until 3:00 because I was missing my mum. In the morning, I was so grumpy... I tried to be nice to them and then Erin's little sister Charlotte started jumping on my back, so I said get off, Charlotte, right now, and I kind of made her cry. (Kate)

Sometimes boredom was attributed to the reason for being sleepy or wanting to sleep as it was the only thing to do in when they did not want to engage in the task at hand.

I think that the children are working. One was kind of bored, so I think she fell asleep... because maybe they're doing a subject that she doesn't like. (Lily)

Well someone's obviously getting bored of work or had a late night and sleeping in class, like asleep or something like that. (Phoebe)

Mental Fatigue.

Children described the experience of "thinking nothing" (Alexander) or the mind being "blank" (Daniel) when feeling mentally fatigued.

Just not thinking about anything really; just blocking everything out I guess. (Jemima).

Although this was similar to experiences shared in relation to sleepiness, the difference here is that engaging in a cognitive task preceded the tiredness. Further, sometimes children talked about not being able to or not "really wanting to concentrate on anything" (Catherine) or wanting to "give up" (Hannah) when they had already been working for a period of time.

Maybe because she didn't want to - I'm not sure. Maybe because she couldn't concentrate. After the test her mind would have been all like fuzzy and stuff... it's like you can't concentrate and you don't know what's going on and stuff. (Hannah)

It feels really - I don't know how to explain it because it feels really weird like nothing else can - if someone's trying to explain something to you, you just can't get it in; it will just not go in. (Jemima)

A few children talked about mental fatigue affecting memory, that they would be unable to remember specific knowledge they had previously learned because of being overwhelmed by cognitive tasks.

Because he probably forgot how to play the piano because he's thinking about all the tests and stuff. (Alexander)

Sometimes [my head] gets a headache and just can't think of anything smart. If you're doing a maths test you can't really think of anything smart. Like your timetables, you can't remember any of them. (Daisy)

They also talked about their brain or head feeling "full of things" (Alexander), "crammed full of information" (Sienna), "overworked" (Phoebe), or simply that their mind was "tired and exhausted" (George).

All muddled up because I did so many tests my head would be all confused and my brain. (Sarah)

Overloaded with information... you just want to think about something else and that's all, one little thing. (Catherine)

Sometimes they talked about experiencing frustration with tasks they were doing when they were fatigued, which made it difficult to complete a task efficiently. The "brain was really tired and stressed" (Benjamin) and children talked about being "fed up" (Clare) or "sick of" (George) doing the mental task at hand.

It just gets so frustrating and you're like, oh, because your brain is getting really worked... yeah, like it – you work your brain so much and it just goes, I can't do anymore. (Lachlan)

The last time I got homework maybe because I got fed up with homework because I have lots of homework and I only had one night to do it and I was really fed up; I didn't want to do the rest. (Clare)

Boredom was more often associated with mental fatigue than sleepiness. When children disliked or were not interested in a certain task, they would label it as boring and wanted to do something different. The want to sleep or feeling sleepy was also associated with boredom in the context of mental fatigue.

Just like she's bored because she's doing a puzzle. I'd be like that as well... you get sleepy when you're bored... yeah, well that's what I do, which I get at school because I find school boring. (Ethan)

Start looking around the room - not necessarily looking around the room but you start getting like I just can't be bothered doing anything or talking. This is just not worth it, yeah... you just don't feel like doing anything when you're bored. It's almost like sleeping. (Benjamin)

Physical Fatigue.

Very few children talked about cognitive processes or emotional experiences in relation to physical fatigue. When emotions did arise in discussion, sadness was sometimes associated with fatigue following physical activity when performance in sport or games was poor.

He's feeling a bit sad that everyone else is still running and then he's just really tired. (Eloise)

Everybody is running and they all look a bit tired because they've just done a bit of sprinting. Maybe they're a bit upset because they didn't win. (Lucy)

Sometimes, loss of motivation was associated with physical fatigue.

I felt drowsy like I couldn't - first I was all excited, I had energy. Then because we do these things and stuff, sometimes I get - I can't be bothered seeing because I get really tired and lose my energy. Then I just start walking in places, not really caring if I win or something like that. (Grace)

Emotional Fatigue.

The notion of an 'emotional fatigue' or 'emotional exhaustion' sometimes arose in children's talk, despite not being prompted. It was contrasted against sleepiness as its own type of or reason for fatigue.

Sleepy you just want to go to sleep and tired sometimes a bit stressed...
(Sienna)

Body-based sensations were sometimes associated with emotional fatigue, usually with the head specifically, feeling 'dizzy' or 'hot'. These sensations were similar to those that children associated with mental fatigue and sleepiness. However, it is the identification of emotion as at least part of the cause of tiredness that children talk about.

I start feeling a bit dizzy and I just feel really emotionally exhausted and stuff like that. (Phoebe)

I often feel hot when I am tired because it sometimes makes me a little bit stressed when I'm tired... you have so many things to do but can't always remember what you have to do to get them right... last time I was stressed when I was packing my costumes in the car ready to go and do a performance... I was a little bit tired, but not too tired. (Annabel)

In addition, children talked about fatigue which followed stress caused by time pressure to complete cognitive tasks, such as homework.

Because he's just done a stressful test and he's been trying to concentrate a lot, and that will make the brain all black; tired and want to sleep or just sit down. (Oscar)

The last time I got homework maybe because I got fed up with homework because I have lots of homework and I only had one night to do it and I was really fed up; I didn't want to do the rest. (Clare)

Chapter 4: Discussion

4.1 Overview

This study aimed to qualitatively explore how children talk about and distinguish between sleepiness and types of fatigue. Two overarching themes and four subthemes were identified that capture children's perspectives of these concepts. Objective descriptions encompassed behavioural causes and responses, while subjective descriptions were related to internal body-based sensations and mind-based experiences. The results suggest that children make a variety of distinctions between sleepiness, mental and physical fatigue through language. Additionally, an unexpected finding in children's language was the notion of 'emotional fatigue' or 'exhaustion'.

4.2 Objective Descriptions

4.2.1 Causes Which Distinguish Between Sleepiness and Fatigue

Where children's language most clearly delineated sleepiness and types of fatigue was in relation to the observable cause of tiredness. Reflecting previous literature, children talked about the cause of sleepiness as insufficient sleep often caused by their own behaviour around bedtime (Nevsimalova, 2017). Such behaviours ranged from being social to watching television or using a computer, highlighting the increasing problem of technology use around bedtime (Hale & Guan, 2015). Mental and physical fatigue shared a common cause of excessive or prolonged activity. Mental fatigue followed cognitive tasks, which aligns with definitions of mental fatigue in the literature (Boksem & Tops, 2008). Physical fatigue, however, was caused by physical exertion and sometimes the individual factor of being unfit or unprepared physically for exercise.

4.2.2 Similarities in Behavioural Responses

When talking about behavioural responses, children described the desire to sleep when sleepy, and the desire to rest, relax, and sometimes sleep, when mentally, or physically fatigued. Where these responses were similar, in terms of needing sleep or rest, the preceding activity or experience distinguished one from another. Namely, sleepiness related to lack of sleep, mental fatigue to cognitive activity, and physical fatigue to physical exertion. Another distinguishing factor was the time of day that tiredness occurred. Children talked about sleepiness occurring in the morning and continuing throughout the day, whereas mental or physical fatigue usually occurred later in the day, typically following or coinciding with a certain activity. Mental and physical fatigue were associated with the desire to disengage with the activity at hand and to rest, relax, or sometimes sleep. However, mental fatigue was uniquely related to wanting to engage in a different activity instead of solely wanting to stop.

The ways in which children's language distinguishes between behavioural responses to sleepiness and fatigue in this study, suggests a problem with existing measures. For example, as mentioned in the introduction, the ESS-CHAD, the modified version of the adult ESS (Johns, 1991), measures an individual's self-perceived sleep propensity in different situations. The language used in this measure was only slightly altered for use with children in two items. Based on the results of this study, it is possible that a measure such as this one misattributes the behavioural response of falling asleep given it was the *cause* rather than the *fact* of the tiredness children identified which ultimately distinguished one concept from another. Therefore, a fatigued child could be incorrectly diagnosed as sleepy.

4.3 The Overlap of Objective and Subjective Descriptions

4.3.1 Cognitive and Behavioural Responses

The behavioural responses to sleepiness and fatigue as discussed above are observable, and therefore clearly fall within objective descriptions. Other behavioural responses are closely associated with the subjective mind-based experiences in children's language. For example, children's talk about subjective cognitive difficulties as a result of sleepiness and fatigue becomes apparent in the display of inattentive behaviours, and

therefore overall impaired performance at school. As discussed in the introduction, sleepiness can affect a child's cognitive flexibility, abstract thinking, motor skills, attention/response inhibition, memory, and focused attention, which can be interpreted as behavioural problems (Calhoun et al., 2012; Dahl, 1996; Fallone et al., 2002). Some research has suggested an overlap of symptoms of sleepiness and ADHD (Dahl, 1996; Golan et al., 2004). However, in the current study, although children talked about both the subjective and objective descriptions of inattention and distraction, they did not describe hyperactive behaviour. This supports a finding in a study by Fallone et al. (2001) that noted inattentive but not hyperactive behaviours in a sample of sleepy children.

In relation to mental fatigue, children also talked about difficulties with focused and sustained attention, and memory, issues evident in the literature on children with CFS (Haig-Ferguson et al., 2009). Further, previous literature also noted that both sleepiness and fatigue affected children's memory, however, the current participants talked about it only in relation to mental fatigue. In addition to unique features of mental fatigue, children talked of 'fiddling' and wanting to 'give up' when feeling overwhelmed by the cognitive task at hand. This response is similar to that exhibited by children with CFS, where stress was expressed through irritability with tasks, including fidgeting or giving up (Haig-Ferguson et al., 2009).

Impaired performance was also common to all three phenomena in children's language either in the classroom or in physical activity. Sleepiness and mental fatigue caused children to work less efficiently, while physical fatigue caused children to be slower and less effective in exerting themselves. General impairment of performance at school was reflected in the literature for both sleepiness and fatigue (Crawley et al., 2011; Ludwig et al., 2019a; Perfect et al., 2014).

In relation to classroom conduct and school performance, the TDSQ, outlined in the introduction, asks teachers whether they observe some of these behavioural responses in the

classroom and how frequently they occur (Owens 1999). Children's language in this study described their awareness that a teacher may notice their behaviour indicating sleepiness or fatigue. This suggests that the same information that could be obtained through adult observation could also be obtained through child self-report. This is valuable as administering a self-report questionnaire to a child avoids relying on the availability of a teacher who is responsible for an entire class. Additionally, due to their duty to attend to all children, particular behaviours of an individual child may be missed, which could lead to underreporting of symptoms in children.

4.3.2 Social Implications of Emotion-Based Behaviour

In addition to non-compliance of behavioural expectations in the classroom, children also talked about non-participation in relation to playing at lunchtime and social interactions at school generally. Children talked about how daily social interactions, usually with friends, were adversely affected by sleepiness but not types of fatigue. However, the reverse is documented in previous literature where social impacts of fatigue have been explored (Ali et al., 2019).

Children talked about feeling 'grumpy' as a result of sleepiness, which is reflected in previous literature where children who experience EDS can also experience a decrease in positive mood. (Alfano et al., 2009). Grumpiness, anger or annoyance are subjective emotions that children experience, although the responses to these emotions are often apparent in children's talk about behaviour and social interactions in relation to sleepiness. Previous literature notes that sleepiness in children is associated with irritability, emotional lability, and low thresholds for expressing frustration and distress (Dahl, 1996). This inability to adequately regulate their emotions becomes apparent through behaviour (Pesonen et al., 2010).

Although children spoke about mind-based experiences of sleepiness and mental fatigue frequently, subjective cognitive and emotional language occurred much less in relation to physical fatigue. However, where children did offer mind-based language about physical fatigue, they spoke of sadness or loss of motivation, usually related to impaired performance or lack of success in any given sport or activity.

4.4 Subjective Descriptions

4.4.1 Distinguishing Features of Body-Based Sensations

When children talked about sensations within the body, distinguishing features were the location, variation, and frequency of pain or unpleasant sensations. There was a focus on talk about pain or other sensations in relation to the eyes and head when describing sleepiness and mental fatigue. However, when children talked about sleepiness, the eyes and head would typically hurt following lack of sleep, whereas for mental fatigue the same sensation was experienced after staring at a screen or page as part of a cognitive task. A unique body-based feature of sleepiness was a weak feeling in the body upon waking. In relation to mental fatigue, children talked about experiencing soreness or aching as a result of overuse of some body parts, such as hands and fingers, while other body parts, such as legs, experienced numbness related to disuse. Physical fatigue was most often associated with the chest, arms, and legs, and children more frequently talked about pain in comparison to language about sleepiness and mental fatigue. A unique sensation of physical fatigue was that of being 'puffed out' following physical exertion.

Though children did make specific distinctions about sensations within the body, they often initially shared that they would feel simply 'tired' in response to scenarios relating to sleepiness, mental, and physical fatigue. This could be problematic as some measures use the word 'tired' to measure solely sleepiness or fatigue. For example, as outlined in the introduction, the PedsQL MFS asks children to rate their level of agreement on 18 items

relating to fatigue (Varni et al., 2004). One item states 'I feel tired', while another states 'I feel tired when I wake up in the morning' (Varni et al., 2004, p. 2495). Both of these responses could also relate to sleepiness. According to children's language in this study, sleepiness was associated with the morning while fatigue was associated with later in the day and after certain activities. In the current study, children used the word 'tired' to refer to sleepiness, mental and physical fatigue, and it was the nature of the scenarios presented which distinguished one concept from another.

4.4.2 Emotional Fatigue

The results of this study suggest that there may be an additional area of emotional fatigue, as reflected in children's language. This phenomenon was not considered in the original design of this study and children talked about it without being prompted. In some instances, children were clear in their language that tiredness was related to emotions they experienced, such as being 'emotionally exhausted'. At other times, this language overlapped with language describing mental fatigue. For example, in responses to the scenarios corresponding to mental fatigue, children talked about emotions such as frustration or feeling overwhelmed with the cognitive task at hand and the combination of cognitive strain and emotions resulted in fatigue.

In the literature, the notion of emotional fatigue has been noted in the context of burnout in the workplace (Alenezi et al., 2019; Ilies et al., 2015). A definition of emotional fatigue in a workplace context according to Maslach (1982) is the state of feeling 'overwhelmed, drained, and used up' based on emotional demands imposed by others (Barnes & Van Dyne, 2009, p. 75). However, it has not been discussed outside this context with adults, and not at all in children. Based on children's language in relation to emotional fatigue in this study, and the aforementioned sparse literature on the concept, emotional fatigue in children could be conceptualised as 'a sense of exhaustion which follows a period of

experiencing a heightened emotional state'. It will be important for future prospective investigations of the veracity and impact of emotional fatigue in children, as distinct from physical and mental fatigue manifestations.

4.5 Children's Ability to Distinguish Between Sleepiness and Fatigue

As previously discussed, Ludwig et al. (2019b) found that most children were able to give acceptable definitions to certain words, such as 'sleepy' and tired' but struggled to give acceptable definitions for other sleep-related words like 'drowsy' and 'alert', suggesting children are not able to adequately comprehend vocabulary used in many current sleepiness measures. However, the results of this study suggest that children are able to articulate distinguishing features of sleepiness and types of fatigue, which supports the assertion by Paavonen et al. (2000) that children are able to adequately give information on symptoms when the methodological means are developmentally appropriate. Considering this research alongside children's language in this study, it may be beneficial for child self-report measures to focus more on the reporting of distinguishing symptoms rather than on direct terms related to either sleepiness or fatigue.

4.6 Strengths

A clear strength of this research is its contribution to the dearth of literature on the child's perspective of sleepiness and fatigue. To the researcher's knowledge, this is the first qualitative study that aimed to understand children's language around both sleepiness and types of fatigue with a focus on distinguishing features in children's expressive language. Employing qualitative research methods to explore children's language around sleepiness and fatigue allowed a detailed understanding of both the nuances of children's talk and the various ways they distinguished between each concept. This advantage of the interviews was reflected in the fact that even though children gave an 'I don't know' or 'they're the same' answer to being directly asked if being sleepy or tired were the same, they nonetheless

identified unique or distinguishing features of each concept throughout the interview. Further, the use of the visual and audio scenarios relating to sleepiness and fatigue were developed with the aim for use with children. The methodology of extraction of information was developmentally appropriate and was therefore able to elicit a rich variety of responses from children around sleepiness and fatigue (Paavonen et al., 2000).

The inclusion of interviews after data saturation was achieved, further enhanced the richness of the data. An audit trail was kept throughout analysis, which allowed the researcher to keep track of all steps of analysis, recording any possible themes, research ideas and processes (Tracy, 2010). The involvement of a second researcher in the cross-checking of coding also decreased the chance of individual bias on the results.

4.7 Implications

This study gives a much-needed insight into how children talk about both objective and subjective experiences of sleepiness and types of fatigue. It shows that children can make a distinction between sleepiness and fatigue, and they do so in many ways. The understanding gained from this study has the potential to inform future development of subjective self-report measures of sleepiness and fatigue in children, therefore improving the identification of these symptoms in children and facilitating a more accurate diagnostic approach to different conditions. More specifically, some of children's language encompasses behaviours that others may observe in daily life, and reflects what researchers, parents, and teachers have observed in previous research. The knowledge that children are self-aware of their behaviour and the causes behind it is important in terms of theory and clinical practice. If researchers and medical professionals are able to rely more on child self-report and less on parent-report and observation, time and expense incurred during screening and diagnosis could be significantly decreased, in addition to providing more accurate assessment, facilitating a more efficient and effective process overall.

4.8 Limitations and Suggestions for Future Research

The data were collected from various primary schools in Adelaide. The variety of schools, SES rankings, grade levels, and balance of genders of participants was a strength of this study. Nonetheless, recruitment of children from public primary schools in Adelaide could limit the generalisability of this study. Further, as this study was conducted in English with native English-speaking children, the results of this study may not be further generalisable to other cultural contexts, and particularly different languages. Finally, as this data were previously collected for a study with larger scope for analysis, demographic data outlined above was collected, however, a quantitative comparison involving these variables was beyond the scope of this study. Future research could explore any association between demographic variables and children's ability to articulate features of sleepiness and fatigue.

During interviews, children were prompted to talk about the social implications of sleepiness, following listening to audio scenarios one and two where the character did not get adequate sleep before attending school. Fatigue was usually talked about in the context of the end of the day or following an activity, reflecting the fatigue-related scenarios, with (unlike other scenarios) no further prompt questions regarding social interactions. This may have limited opportunity to discuss any social implications with friends. This did not allow for an unbiased comparison of the social aspect of sleepiness and types of fatigue, which may have limited further examination of children's understanding of behavioural responses.

The indication of an emotional fatigue component in the broader conceptualisation of fatigue from a child's perspective is particularly important given children noted a similar degree of impact from this type of fatigue as compared mental and physical fatigue as well as sleepiness. The implication that emotional fatigue could have serious negative consequences for children's wellbeing is suggestive of a need for further investigation of emotional fatigue in children.

4.9 Conclusion

This study is the first to qualitatively explore the child's perspectives of sleepiness and fatigue. A key outcome of this study was confirmation of children's ability to distinguish between sleepiness, mental and physical fatigue, and identification of the language they use to name features which distinguish one phenomenon from another. Some of the children's objective and subjective descriptions of their experiences of sleepiness and fatigue were reflected in previous research, but the concept and significance of children's experience of emotional fatigue is a novel finding. The understanding of children's language gained from this study has important theoretical and clinical implications for future diagnostic approaches and assessment techniques of sleepiness and fatigue in children.

References

Alenezi, A., McAndrew, S., & Fallon, P. (2019). Burning out physical and emotional fatigue: Evaluating the effects of a programme aimed at reducing burnout among mental health nurses. *International Journal of Mental Health Nursing*, 1045-1055. https://doi.org/http://dx.doi.org/10.1111/inm.12608

Alfano, C. A., Zakem, A. H., Costa, N. M., Taylor, L. K., & Weems, C. F. (2009). Sleep problems and their relation to cognitive factors, anxiety, and depressive symptoms in children and adolescents. *Depress Anxiety*, 26(6), 503-512. https://doi.org/10.1002/da.20443

Ali, S., Adamczyk, L., Burgess, M., & Chalder, T. (2019, Oct). Psychological and demographic factors associated with fatigue and social adjustment in young people with severe chronic fatigue syndrome/myalgic encephalomyelitis: a preliminary mixed-methods study. *J Behav Med*, 42(5), 898-910. https://doi.org/10.1007/s10865-019-00010-x

Barnes, C. M., & Van Dyne, L. (2009). 'I'm tired': Differential effects of physical and emotional fatigue on workload management strategies [Personnel Evaluation & Job Performance 3630]. *Human Relations*, 62(1), 59-92.

https://doi.org/http://dx.doi.org/10.1177/0018726708099518

Barter, C., & Renold, E. (2000). 'I wanna tell you a story': Exploring the application of vignettes in qualitative research with children and young people [Research Methods & Experimental Design 2260]. *International Journal of Social Research Methodology: Theory & Practice*, 3(4), 307-323. https://doi.org/http://dx.doi.org/10.1080/13645570050178594

Benmedjahed, K., Wang, Y. G., Lambert, J., Evans, C., Hwang, S., Black, J., & Johns, M. W. (2017, Apr). Assessing sleepiness and cataplexy in children and adolescents with narcolepsy: a review of current patient-reported measures. *Sleep Med*, *32*, 143-149. https://doi.org/10.1016/j.sleep.2016.12.020

Bioulac, S., Taillard, J., Philip, P., & Sagaspe, P. (2020). Excessive Daytime Sleepiness Measurements in Children With Attention Deficit Hyperactivity Disorder. *Front Psychiatry*, 11, 3. https://doi.org/10.3389/fpsyt.2020.00003

Blunden, S., Lushington, K., Lorenzen, B., Ooi, T., Fung, F., & Kennedy, D. (2004, Aug). Are sleep problems under-recognised in general practice? *Arch Dis Child*, 89(8), 708-712. https://doi.org/10.1136/adc.2003.027011

Boksem, M. A., & Tops, M. (2008, Nov). Mental fatigue: costs and benefits. *Brain Res Rev*, 59(1), 125-139. https://doi.org/10.1016/j.brainresrev.2008.07.001

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology [Research Methods & Experimental Design 2260]. *Qualitative Research in Psychology*, *3*(2), 77-101. https://doi.org/http://dx.doi.org/10.1191/1478088706qp063oa

Brigden, A., Loades, M., Abbott, A., Bond-Kendall, J., & Crawley, E. (2017, Oct). Practical management of chronic fatigue syndrome or myalgic encephalomyelitis in childhood. *Arch Dis Child*, *102*(10), 981-986. https://doi.org/10.1136/archdischild-2016-310622

Bruni, O., Ferini-Strambi, L., Russo, P. M., Antignani, M., Innocenzi, M., Ottaviano, P., Valente, D., & Ottaviano, S. (2006, Jan). Sleep disturbances and teacher ratings of school achievement and temperament in children. *Sleep Med*, 7(1), 43-48.

https://doi.org/10.1016/j.sleep.2005.09.003

Bruni, O., Ottaviano, S., Guidetti, V., Romoli, M., Innocenzi, M., Cortesi, F., & Giannotti, F. (1996, Dec). The Sleep Disturbance Scale for Children (SDSC). Construction and validation of an instrument to evaluate sleep disturbances in childhood and adolescence. *J Sleep Res*, 5(4), 251-261. https://doi.org/10.1111/j.1365-2869.1996.00251.x

Calhoun, S. L., Fernandez-Mendoza, J., Vgontzas, A. N., Mayes, S. D., Tsaoussoglou, M., Rodriguez-Muñoz, A., & Bixler, E. O. (2012, May 1). Learning, attention/hyperactivity,

and conduct problems as sequelae of excessive daytime sleepiness in a general population study of young children. *Sleep*, *35*(5), 627-632. https://doi.org/10.5665/sleep.1818

Calhoun, S. L., Vgontzas, A. N., Fernandez-Mendoza, J., Mayes, S. D., Tsaoussoglou, M., Basta, M., & Bixler, E. O. (2011, Apr 1). Prevalence and risk factors of excessive daytime sleepiness in a community sample of young children: the role of obesity, asthma, anxiety/depression, and sleep. *Sleep*, *34*(4), 503-507. https://doi.org/10.1093/sleep/34.4.503

Carter, K. A., Hathaway, N. E., & Lettieri, C. F. (2014, Mar 1). Common sleep disorders in children. *Am Fam Physician*, 89(5), 368-377.

Chalder, T., Berelowitz, G., Pawlikowska, T., Watts, L., Wessely, S., Wright, D., & Wallace, E. P. (1993). Development of a fatigue scale. *J Psychosom Res*, *37*(2), 147-153. https://doi.org/10.1016/0022-3999(93)90081-p

Collin, S. M., Norris, T., Gringras, P., Blair, P. S., Tilling, K., & Crawley, E. (2018, Jun). Childhood sleep and adolescent chronic fatigue syndrome (CFS/ME): evidence of associations in a UK birth cohort. *Sleep Med, 46*, 26-36.

https://doi.org/10.1016/j.sleep.2018.01.005

Crawley, E. (2017). Pediatric chronic fatigue syndrome: current perspectives.

Pediatric Health Med Ther, 9, 27-33. https://doi.org/10.2147/phmt.S126253

Crawley, E., Hunt, L., & Stallard, P. (2009, Nov). Anxiety in children with CFS/ME. Eur Child Adolesc Psychiatry, 18(11), 683-689. https://doi.org/10.1007/s00787-009-0029-4

Crawley, E. M., Emond, A. M., & Sterne, J. A. (2011). Unidentified Chronic Fatigue Syndrome/myalgic encephalomyelitis (CFS/ME) is a major cause of school absence: surveillance outcomes from school-based clinics. *BMJ Open, 1*(2), e000252.

https://doi.org/10.1136/bmjopen-2011-000252

Dahl, R. E. (1996, Mar). The impact of inadequate sleep on children's daytime cognitive function. *Semin Pediatr Neurol*, *3*(1), 44-50. https://doi.org/10.1016/s1071-9091(96)80028-3

Dewald, J. F., Meijer, A. M., Oort, F. J., Kerkhof, G. A., & Bögels, S. M. (2010, Jun). The influence of sleep quality, sleep duration and sleepiness on school performance in children and adolescents: A meta-analytic review. *Sleep Med Rev, 14*(3), 179-189. https://doi.org/10.1016/j.smrv.2009.10.004

Drake, C., Nickel, C., Burduvali, E., Roth, T., Jefferson, C., & Badia, P. (2003). The pediatric daytime sleepiness scale (PDSS): Sleep habits and school outcomes in middle-school children [Developmental Scales & Schedules 2222]. *Sleep: Journal of Sleep and Sleep Disorders Research*, 26(4), 455-458.

Fallone, G., Acebo, C., Arnedt, J. T., Seifer, R., & Carskadon, M. A. (2001, Aug). Effects of acute sleep restriction on behavior, sustained attention, and response inhibition in children. *Percept Mot Skills*, *93*(1), 213-229. https://doi.org/10.2466/pms.2001.93.1.213

Fallone, G., Owens, J. A., & Deane, J. (2002, Aug). Sleepiness in children and adolescents: clinical implications. *Sleep Med Rev, 6*(4), 287-306.

https://doi.org/10.1053/smrv.2001.0192

Farmer, A., Fowler, T., Scourfield, J., & Thapar, A. (2004, Jun). Prevalence of chronic disabling fatigue in children and adolescents. *Br J Psychiatry*, *184*, 477-481.

https://doi.org/10.1192/bjp.184.6.477

Fowler, T., Duthie, P., Thapar, A., & Farmer, A. (2005, Aug 9). The definition of disabling fatigue in children and adolescents. *BMC Fam Pract*, 6, 33.

https://doi.org/10.1186/1471-2296-6-33

Geraghty, K. J., & Adeniji, C. (2018). The Importance of Accurate Diagnosis of ME/CFS in Children and Adolescents: A Commentary. *Front Pediatr, 6*, 435. https://doi.org/10.3389/fped.2018.00435

Golan, N., Shahar, E., Ravid, S., & Pillar, G. (2004, Mar 15). Sleep disorders and daytime sleepiness in children with attention-deficit/hyperactive disorder. *Sleep*, *27*(2), 261-266. https://doi.org/10.1093/sleep/27.2.261

Gregorowski, A., Simpson, J., & Segal, T. Y. (2019, Aug). Child and adolescent chronic fatigue syndrome/myalgic encephalomyelitis: where are we now? *Curr Opin Pediatr*, 31(4), 462-468. https://doi.org/10.1097/mop.00000000000000777

Haig-Ferguson, A., Tucker, P., Eaton, N., Hunt, L., & Crawley, E. (2009, Oct). Memory and attention problems in children with chronic fatigue syndrome or myalgic encephalopathy. *Arch Dis Child*, *94*(10), 757-762. https://doi.org/10.1136/adc.2008.143032

Hale, L., & Guan, S. (2015, Jun). Screen time and sleep among school-aged children and adolescents: a systematic literature review. *Sleep Med Rev, 21*, 50-58.

https://doi.org/10.1016/j.smrv.2014.07.007

Ho, K. Y., Li, W. H. C., Lam, K. W. K., Wei, X., Chiu, S. Y., Chan, C. G., & Chung, O. K. J. (2019, Feb). Relationships among fatigue, physical activity, depressive symptoms, and quality of life in Chinese children and adolescents surviving cancer. *Eur J Oncol Nurs*, 38, 21-27. https://doi.org/10.1016/j.ejon.2018.11.007

Hoban, T. F., & Chervin, R. D. (2001, Dec). Assessment of sleepiness in children. Semin Pediatr Neurol, 8(4), 216-228. https://doi.org/10.1053/spen.2001.29043

Hockenberry, M. J., Hinds, P. S., Barrera, P., Bryant, R., Adams-McNeill, J., Hooke, C., Rasco-Baggott, C., Patterson-Kelly, K., Gattuso, J. S., & Manteuffel, B. (2003, Apr).

Three instruments to assess fatigue in children with cancer: the child, parent and staff

perspectives. J Pain Symptom Manage, 25(4), 319-328. https://doi.org/10.1016/s0885-3924(02)00680-2

Ilies, R., Huth, M., Ryan, A. M., & Dimotakis, N. (2015). Explaining the links between workload, distress, and work-family conflict among school employees: Physical, cognitive, and emotional fatigue [Educational Administration & Personnel 3510]. *Journal of Educational Psychology*, 107(4), 1136-1149.

https://doi.org/http://dx.doi.org/10.1037/edu0000029

Janssen, K. C., Phillipson, S., O'Connor, J., & Johns, M. W. (2017, May). Validation of the Epworth Sleepiness Scale for Children and Adolescents using Rasch analysis. *Sleep Med*, 33, 30-35. https://doi.org/10.1016/j.sleep.2017.01.014

Jason, L. A., Evans, M., Brown, M., & Porter, N. (2010, May). What is fatigue? Pathological and nonpathological fatigue. *Pm r, 2*(5), 327-331.

https://doi.org/10.1016/j.pmrj.2010.03.028

Johns, M. W. (1991, Dec). A new method for measuring daytime sleepiness: the Epworth sleepiness scale. *Sleep, 14*(6), 540-545. https://doi.org/10.1093/sleep/14.6.540

Johns, M. W. (2000, Mar). Sensitivity and specificity of the multiple sleep latency test (MSLT), the maintenance of wakefulness test and the epworth sleepiness scale: failure of the MSLT as a gold standard. *J Sleep Res, 9*(1), 5-11. https://doi.org/10.1046/j.1365-2869.2000.00177.x

Jones, C. M., DeWalt, D. A., & Huang, I. C. (2017, Nov-Dec). Impaired Patient-Reported Outcomes Predict Poor School Functioning and Daytime Sleepiness: The PROMIS Pediatric Asthma Study. *Acad Pediatr*, *17*(8), 850-854.

https://doi.org/10.1016/j.acap.2017.07.010

Kawatani, J., Mizuno, K., Shiraishi, S., Takao, M., Joudoi, T., Fukuda, S., Watanabe, Y., & Tomoda, A. (2011, Nov). Cognitive dysfunction and mental fatigue in childhood

chronic fatigue syndrome--a 6-month follow-up study. *Brain Dev, 33*(10), 832-841. https://doi.org/10.1016/j.braindev.2010.12.009

Kazaglis, L., Molero, H., Azeem, M. W., & Khawaja, I. S. (2016). Overview and management of common sleep disorders in children: A review for psychiatrists [Health & Mental Health Treatment & Prevention 3300]. *Psychiatric Annals*, 46(1), 39-44. https://doi.org/http://dx.doi.org/10.3928/00485713-20151209-01

Lewandowski, A. S., Toliver-Sokol, M., & Palermo, T. M. (2011). Evidence-based review of subjective pediatric sleep measures [Developmental Psychology 2800]. *Journal of Pediatric Psychology, 36*(7), 780-793. https://doi.org/http://dx.doi.org/10.1093/jpepsy/jsq119 Liamputtong, P. (2020). *Qualitative Research Methods* (Fifth ed.). Oxford University Press.

Lim, E. J., Ahn, Y. C., Jang, E. S., Lee, S. W., Lee, S. H., & Son, C. G. (2020, Feb 24). Systematic review and meta-analysis of the prevalence of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). *J Transl Med, 18*(1), 100. https://doi.org/10.1186/s12967-020-02269-0

Ludwig, B., Smith, S. S., & Heussler, H. (2019a). Exploring the association between perceived excessive daytime sleepiness in children and academic outcomes [Article]. *Issues in Educational Research*, 29(3), 841-857. https://www.scopus.com/inward/record.uri?eid=2-s2.0-85071370981&partnerID=40&md5=e93c76ffe9dbe196f790a268df51b9a6

Ludwig, B., Smith, S. S., & Heussler, H. (2019b, Jan). How Well Do Children Understand the Vocabulary of Sleep? *Health Lit Res Pract*, *3*(1), e53-e69. https://doi.org/10.3928/24748307-20190122-01

Maher, C., Crettenden, A., Evans, K., Thiessen, M., Toohey, M., Watson, A., & Dollman, J. (2015, Aug). Fatigue is a major issue for children and adolescents with physical disabilities. *Dev Med Child Neurol*, *57*(8), 742-747. https://doi.org/10.1111/dmcn.12736

Marriner, A. M., Pestell, C., Bayliss, D. M., McCann, M., & Bucks, R. S. (2017, Oct). Confirmatory factor analysis of the Sleep Disturbance Scale for Children (SDSC) in a clinical sample of children and adolescents. *J Sleep Res*, 26(5), 587-594.

https://doi.org/10.1111/jsr.12526

Melendres, M. C., Lutz, J. M., Rubin, E. D., & Marcus, C. L. (2004, Sep). Daytime sleepiness and hyperactivity in children with suspected sleep-disordered breathing. *Pediatrics*, 114(3), 768-775. https://doi.org/10.1542/peds.2004-0730

Moreira, G. A., & Pradella-Hallinan, M. (2017). Sleepiness in children: An update [Physical & Somatoform & Psychogenic Disorders 3290]. *Sleep Medicine Clinics*, *12*(3), 407-413. https://doi.org/http://dx.doi.org/10.1016/j.jsmc.2017.03.013

Morrison, I., & Riha, R. L. (2012, Mar). Excessive daytime sleepiness and narcolepsy--an approach to investigation and management. *Eur J Intern Med*, *23*(2), 110-117. https://doi.org/10.1016/j.ejim.2011.09.005

Nevsimalova, S. (2017). Disorders associated with increased sleepiness [Physical & Somatoform & Psychogenic Disorders 3290]. *Sleep disorders in children.*, 281-304. https://doi.org/http://dx.doi.org/10.1007/978-3-319-28640-2_13

Owens, J. (2008, Sep). Classification and epidemiology of childhood sleep disorders. *Prim Care*, 35(3), 533-546, vii. https://doi.org/10.1016/j.pop.2008.06.003

Owens, J., Maxim, R., McGuinn, M., Nobile, C., Msall, M., & Alario, A. (1999, Sep). Television-viewing habits and sleep disturbance in school children. *Pediatrics*, *104*(3), e27. https://doi.org/10.1542/peds.104.3.e27

Owens, J. A., Spirito, A., & McGuinn, M. (2000, Dec 15). The Children's Sleep Habits Questionnaire (CSHQ): psychometric properties of a survey instrument for schoolaged children. *Sleep*, *23*(8), 1043-1051.

Paavonen, E. J., Aronen, E. T., Moilanen, I., Piha, J., Räsänen, E., Tamminen, T., & Almqvist, F. (2000, Feb). Sleep problems of school-aged children: a complementary view. *Acta Paediatr*, 89(2), 223-228. https://doi.org/10.1080/080352500750028870

Parslow, R. M., Harris, S., Broughton, J., Alattas, A., Crawley, E., Haywood, K., & Shaw, A. (2017, Jan 13). Children's experiences of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): a systematic review and meta-ethnography of qualitative studies. *BMJ Open*, 7(1), e012633. https://doi.org/10.1136/bmjopen-2016-012633

Patel, M. X., Smith, D. G., Chalder, T., & Wessely, S. (2003, Oct). Chronic fatigue syndrome in children: a cross sectional survey. *Arch Dis Child*, 88(10), 894-898. https://doi.org/10.1136/adc.88.10.894

Perfect, M. M., Levine-Donnerstein, D., Archbold, K., Goodwin, J. L., & Quan, S. F. (2014). The contribution of sleep problems to academic and psychosocial functioning [Educational Psychology 3500]. *Psychology in the Schools*, *51*(3), 273-295. https://doi.org/http://dx.doi.org/10.1002/pits.21746

Pesonen, A. K., Räikkönen, K., Paavonen, E. J., Heinonen, K., Komsi, N., Lahti, J., Kajantie, E., Järvenpää, A. L., & Strandberg, T. (2010, Dec). Sleep duration and regularity are associated with behavioral problems in 8-year-old children. *Int J Behav Med*, *17*(4), 298-305. https://doi.org/10.1007/s12529-009-9065-1

Pigeon, W. R., Sateia, M. J., & Ferguson, R. J. (2003, Jan). Distinguishing between excessive daytime sleepiness and fatigue: toward improved detection and treatment. *J Psychosom Res*, *54*(1), 61-69. https://doi.org/10.1016/s0022-3999(02)00542-1

QSR International Pty Ltd. (2020) NVivo (released in March 2020), h. w. q. c. n.-q.-d.-a.-s. h.

Shahid, A., Shen, J., & Shapiro, C. M. (2010). Measurements of sleepiness and fatigue [Clinical Psychological Testing 2224]. *Journal of Psychosomatic Research*, 69(1), 81-89. https://doi.org/http://dx.doi.org/10.1016/j.jpsychores.2010.04.001

Shen, J., Barbera, J., & Shapiro, C. M. (2006, Feb). Distinguishing sleepiness and fatigue: focus on definition and measurement. *Sleep Med Rev, 10*(1), 63-76. https://doi.org/10.1016/j.smrv.2005.05.004

Snodgrass, K., Harvey, A., Scheinberg, A., & Knight, S. (2015, Jul 15). Sleep Disturbances in Pediatric Chronic Fatigue Syndrome: A Review of Current Research. *J Clin Sleep Med*, 11(7), 757-764. https://doi.org/10.5664/jcsm.4854

Spilsbury, J. C., Drotar, D., Rosen, C. L., & Redline, S. (2007, Oct 15). The Cleveland adolescent sleepiness questionnaire: a new measure to assess excessive daytime sleepiness in adolescents. *J Clin Sleep Med*, *3*(6), 603-612.

Steenbruggen, T. G., Hoekstra, S. J., & van der Gaag, E. J. (2015, Mar 13). Could a change in diet revitalize children who suffer from unresolved fatigue? *Nutrients*, 7(3), 1965-1977. https://doi.org/10.3390/nu7031965

Tracy, S. J. (2010). Qualitative quality: Eight a"big-tent" criteria for excellent qualitative research [Article]. *Qualitative Inquiry*, 16(10), 837-851.

https://doi.org/10.1177/1077800410383121

Varni, J. W., Burwinkle, T. M., Katz, E. R., Meeske, K., & Dickinson, P. (2002, Apr 1). The PedsQL in pediatric cancer: reliability and validity of the Pediatric Quality of Life Inventory Generic Core Scales, Multidimensional Fatigue Scale, and Cancer Module. *Cancer*, 94(7), 2090-2106. https://doi.org/10.1002/cncr.10428

Varni, J. W., Burwinkle, T. M., & Szer, I. S. (2004, Dec). The PedsQL Multidimensional Fatigue Scale in pediatric rheumatology: reliability and validity. *J Rheumatol*, 31(12), 2494-2500.

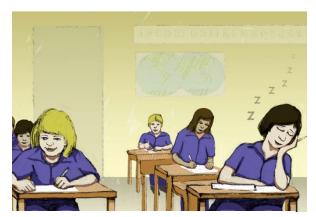
Weinberg, W. A., & Harper, C. R. (1993, Feb). Vigilance and its disorders. *Neurol Clin*, 11(1), 59-78.

Yeh, E. A. (2016, Mar). Fatigue in childhood multiple sclerosis. *Dev Med Child Neurol*, *58*(3), 218. https://doi.org/10.1111/dmcn.13055

Zafar, A. B., Ness, J., Dowdy, S., Avis, K., & Bashir, K. (2012, Apr). Examining sleep, fatigue, and daytime sleepiness in pediatric multiple sclerosis patients. *Mult Scler*, 18(4), 481-488. https://doi.org/10.1177/1352458511424307

Appendix A: Visual and Audio Interview Prompts

Visual Scenarios



One: Sleepiness: Girl sleeping in class



Two: Physical Fatigue: Boy running



Three: Physical Fatigue: Santa Claus



Four: Mental Fatigue: Girl doing puzzle

Audio Scenarios

Four audio stories depicting either Jack or Emma (depending on gender of the child; Emma for female, Jack for male).

One: Sleepiness (deprivation)

A family had some friends, including adults and kids, over on a Sunday evening to watch a fun movie. Jack/Emma stayed up very late to watch the whole movie. He/she went to bed very, very late after everyone had left. The next morning, Jack/Emma had trouble waking up. Jack/Emma did not want to get out of his/her bed. Jack/Emma knows he/she has to get up and get ready for school. His/her mum has called him twice. Jack/Emma just can't seem to wake up. Jack/Emma falls back to sleep after being awakened.

Two: Sleepiness (disruption)

Jack/Emma went to bed on time and went straight to sleep. In the middle of the night, the neighbour's two dogs started barking, and they woke him/her up. When the barking stopped Jack/Emma went back to sleep. After a while, the barking started again and this woke him/her up again. This happened a lot! The next morning Jack/Emma's mum woke him/her up to get ready for school. Jack/Emma did not want to get out of bed, he/she just wanted to go back to sleep.

Three: Physical Fatigue

It was sports day in Jack/Emma's school. Jack/Emma was very excited in the morning as he/she was taking part in lots of races. At the end of the day Jack/Emma was happy because his/her team won but felt he/she did not have the energy to walk back to his/her classroom. His/her mum came to collect Jack/Emma from school. Instead of going straight home, mum took Jack/Emma shopping to get Jack/Emma's new school shoes. When they got home mum said, "Jack/Emma, don't forget. It's your turn to take the dog out for a walk

before dinner" Jack/Emma did not want to take the dog out for a walk. He/she just wanted to rest.

Four: Mental Fatigue

It was test week in Jack/Emma's school. Jack/Emma had a spelling test on Monday. On Tuesday Jack/Emma had a maths test in morning and an English story writing test in the afternoon. Jack/Emma had to think very hard about the characters in his/her story and pay attention to his/her spelling and keep his/her writing neat. When Jack/Emma came home from school on Tuesday, mum reminded him/her about his/her piano lessons later in the evening. Jack/Emma did not want to have piano lessons, he/she just wanted to rest.